

December 11, 2012



**Maine Developmental
Disabilities Council**

225 Western Avenue
139 State House Station
Augusta, Maine 04333-0139

Phone: 207-287-4213

Fax: 207-287-8001

Toll Free: 800-244-3990

www.MaineDDC.org

**Comments Regarding the MaineCare Redesign Task Force
Recommendations Report**

Chair Mayhew and Members of the MaineCare Redesign Task Force:

Thank you for the opportunity to provide comments on the report you are preparing to submit to the Legislature regarding the MaineCare program and recommendations for redesign of Maine's Medicaid program. We particularly appreciate the task force's attention and commitment to the stated goal in the enabling legislation to assure that Maine will maintain high quality, cost-effective services to populations in need of health coverage. While we recognize that the current fiscal situation jeopardizes that goal, the task force has reflected in its recommendations the comments of several of its members regarding the long-term health and financial implications of eliminating or severely restricting services in the shorter term.

Who We Are

The DD Council is a federally-funded, independent organization with members from across the state, including persons with disabilities, family members, and representatives of public and private agencies that provide services and/or funding for services for individuals with developmental disabilities. As required in federal law, we are involved in advocacy, capacity building and systemic change activities, with the goal that individuals with developmental and other disabilities of all ages are fully included, integrated and involved in their communities and the decisions impacting them.

Respectful Language

The DD Council would like to thank the Department and the Task Force for incorporating several changes suggested by our executive director, Julia Bell, to assure the use of respectful language. As Ms. Bell pointed out in earlier in-person comments to the Task Force, this reflects the changes being adopted by the federal government and also the changes in state statute pursuant to legislation passed last spring (PL 2011 chapter 542, An Act To Implement the Recommendations of the Department of Health and Human Services and the Maine Developmental Disabilities Council Regarding Respectful Language). We note, however, that some of the materials used and made available on the Task Force's website still use terminology and phrasing that does not respect persons with disabilities and thus do not reflect

Maine policy on respectful language. We respectfully request that the Department and Task Force use respectful language on all new materials and that the Department revise existing policies and other materials to use respectful language.

Definition of Developmental Disability

I would like to call your attention to the use of the term “developmental disability” in the draft report. Given the current definitions used in Maine statute regarding eligibility for services, it is misleading to use this term to describe the population receiving services. It is, in fact, a much narrower segment of the population, with higher service needs in most cases, than would be included under the umbrella of “developmental disability.” For example, on page 14 of the report, we suggest the Task Force should use the categorical definitions for eligibility included in Maine statutes to describe the individuals with high costs in the top 5 percent as “individuals with intellectual disabilities and/or autism spectrum disorders.” (Note: this document will henceforth use the term “autism” to include all disorders across the autism spectrum.)

The DD Council uses the federal definition of “developmental disability” in determining the population whose concerns and issues we address. As defined in 42 USC 15002, Section 102, 8(A), a “developmental disability” is a severe chronic disability of an individual that –

- i. is attributable to a mental or physical impairment or combination of mental and physical impairments;
- ii. is manifested before the individual attains age 22;
- iii. is likely to continue indefinitely;
- iv. results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - I. Self-care.
 - II. Receptive and expressive language.
 - III. Learning.
 - IV. Mobility.
 - V. Self-direction.
 - VI. Capacity for independent living.
 - VII. Economic self-sufficiency; and
- v. reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

The federal law also adds that any infant or young child “from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.”

The DD Council feels strongly that it is important to make the distinction in terminology because the state of Maine has very proscriptive eligibility criteria for adults who apply for services under the two waiver programs that comprise most of “Adult Developmental Services” (within the Office of Aging and Disability Services). Any policy decisions affecting those who receive such services should not be predicated on an inaccurate understanding of the population’s composition.

State-Run Institutions and Waiver Expenditures

Eligibility criteria for home- and community-based services waiver programs vary state-by-state, as do the services offered and the settings in which they are available. It is critical, in reviewing any data regarding expenditures for persons with intellectual disabilities or autism, to note that Maine is one of only 11 states, along with the District of Columbia, which has no state-run institutions.

As part of the examination of overall MaineCare costs and those individuals whose annual costs of care are among the highest percentage group, the Department and the Task Force have focused significant attention on individuals eligible for the two Home- and Community-Based Services (HCBS) waivers. The DD Council is concerned that materials reviewed by the Task Force have benchmarked Maine against other states in terms of average total expenditures per waiver recipient, without taking into account that Maine does not have any state-run institutions. The 39 states that have not closed all of their state-run institutions have moved some people into community settings, and some of those states are moving closer to full deinstitutionalization than others. However, in each of them, individuals with the lowest needs for services and supports are the easiest to place in community settings. The individuals with the most complex needs and associated high costs of care are far more likely to still be residing in the institutions. Thus, as pointed out by Task Force member Mary Lou Dyer, any comparison of Maine to all other states in the country is a matter of “comparing apples to oranges.”

As can be seen from Table 1, the annual cost of care per person in a state institution is roughly \$200,000 per year and vastly exceeds the annual cost per individual in any other residential setting.

Table 1. United States Annual Cost of Care per Person in Six Residential Settings.

Fiscal Year	Institutions for 16+ Persons			ICFs/ID for 15 or Fewer Persons		Supported Living/Personal Assistance
	ICF/ID	Non-ICF/ID	State Operated	Private	Public	
2011	\$88,933	\$43,607	\$220,144	\$85,471	\$126,256	\$26,246
2009	\$81,093	\$38,802	\$191,116	\$81,411	\$96,479	\$26,207

Shading indicates type of residential setting that Maine does not provide.

Source: Braddock et al. (2011, 2012)

Quantitatively, the mean expenditure per waiver recipient among states without an institution is 38% larger than the mean expenditure per waiver recipient among states with an institution (see Table 2).

Table 2. Mean Home and Community Based Services Expenditure per Waiver Participant, by Whether a State Operates an Institution.

Fiscal Year	Mean HCBS Expenditure per Waiver Participant	
	States with an Institution	States without an Institution
2011	\$43,648.99	\$60,353.94
2009	\$42,562.44	\$63,915.56

Source: Braddock et al. (2011, 2012)

The variability of numerous factors ranging from eligibility to service array does not invalidate the exercise of comparing states to one another. However, it does mean that the comparisons must be undertaken with care.

The Task Force draft report includes a table that compares MaineCare HCBS expenditures per waiver participant for FY 2009 to national benchmarks. Data from that table are reproduced below in Table 3 (and are augmented by more recent data from FY 2011). Given that Maine does not operate a state institution, it is no surprise that Maine exceeds national averages in waiver expenditures. But two important questions are

1. How do Maine's expenditures stack up against similar states (i.e., those without state institutions), and
2. How are the numbers trending into more recent fiscal years?

Table 3. Average Expenditures per Waiver Participant, Percentiles Across States.

Rank	Average State & Federal Expenditures per Waiver Participant	
	FY 2009	FY 2011
25 th percentile	\$31,161	\$33,733
50 th percentile	\$42,155	\$43,851
US average	\$42,896	\$44,309
75 th percentile	\$51,199	\$55,326
90 th percentile	\$68,478	\$74,260
Maine average	\$77,736	\$66,822

FY 2009 Source: MaineCare Redesign Task Force Draft Report (2012)

FY 2011 Source: Braddock et al. (2012)

The data on state-by-state comparisons is treated graphically below in Figure 1.

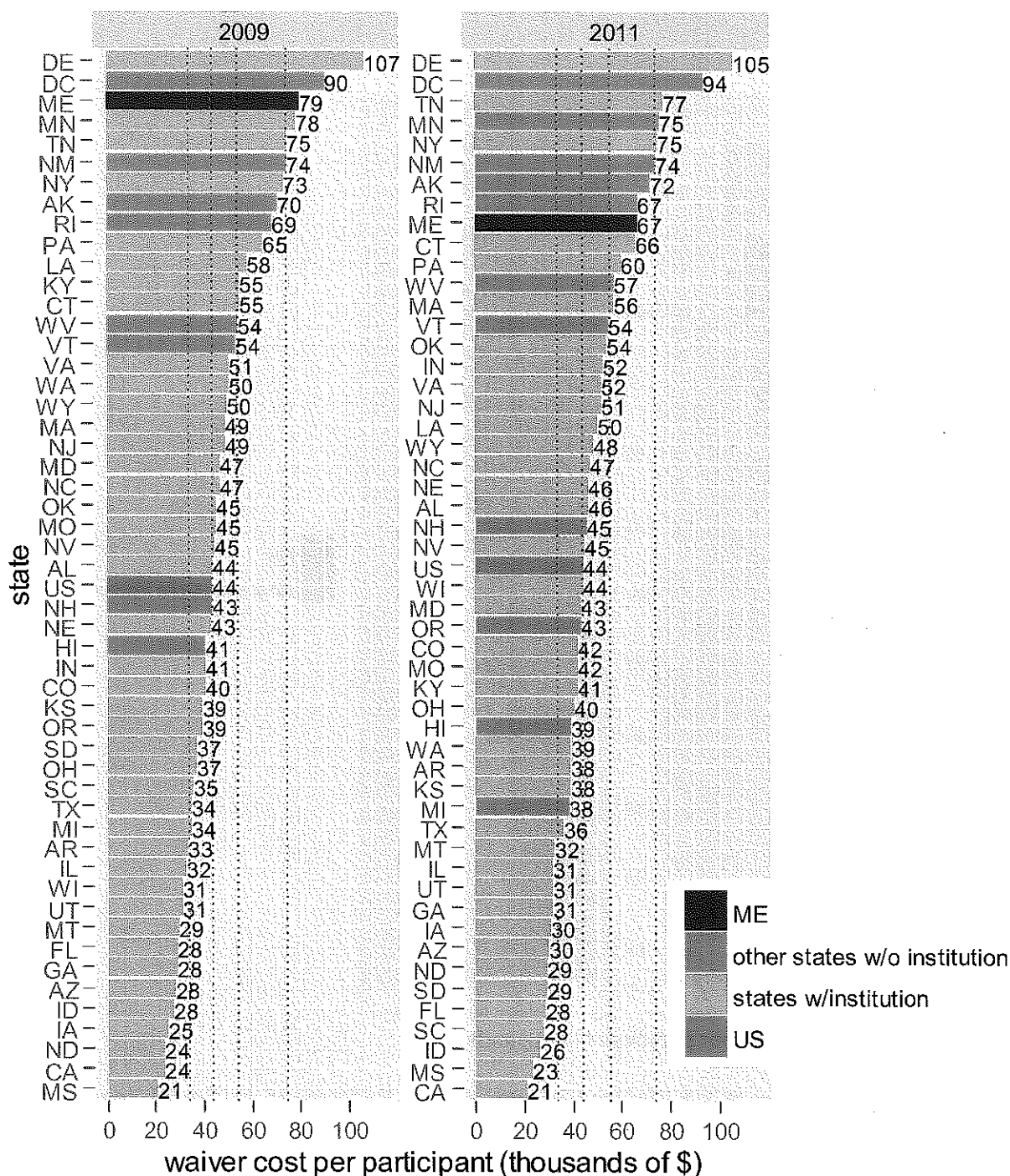


Figure 1. State-by-State HCBS Waiver Cost per Waiver Participant, by Fiscal Year and by Whether the State Operates an Institution. Dotted lines indicate 25th, 50th, 75th, and 90th percentile in each panel. (Source: Braddock et al. (2011, 2012))

The left panel, which shows the FY 2009 data that were summarized in the Task Force draft report, indicates that Maine did indeed spend a significant amount per waiver participant in that year, relative to states that operate a state-run institution (gray bars) and relative to the eight other states that did not operate an institution during that year. However, the right panel, which

shows more recent data (from FY 2011), indicates that Maine's expenditures per waiver participant dropped. Maine still spent more on HCBS per waiver participant than states that did not operate an institution, but Maine now spent roughly the same as other states without a state-run institution.

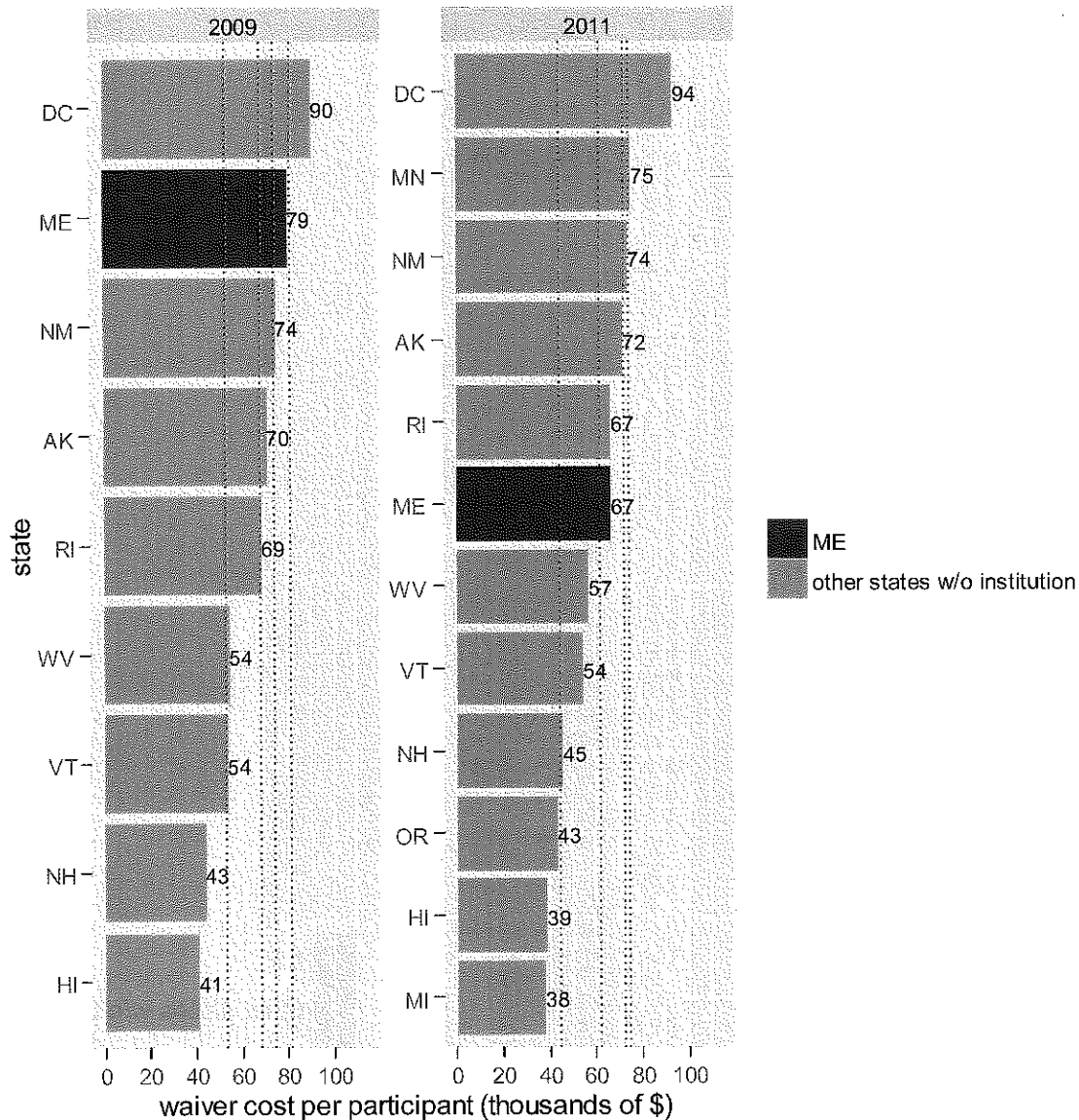


Figure 2. State-by-State HCBS Waiver Cost per Waiver Participant, by Fiscal Year, for States without a State-Run Institution. Dotted lines indicate 25th, 50th, 75th, and 90th percentile in each panel. (Source: Braddock et al. (2011, 2012))

To facilitate the key comparisons with states that did not operate a state-run institution, Figure 2 plots the HCBS waiver data only for those states (9 states in FY 2009 and 12 states in FY 2011, as three additional states had closed their state-run institutions). It is evident from the left panel of Figure 2 that Maine HCBS expenditures per waiver participant were high relative to other states without an institution in FY 2009. But it is equally evident from the right panel of Figure 2 that, by FY 2011, Maine's HCBS expenditures per waiver recipient had fallen to almost the median among states not operating institutions.

The data in Figure 2 suggest that, at least as of FY 2011, Maine's HCBS expenditures were not out-of-line with other states not operating institutions.

Supported Living /Family Support

This is not intended to suggest that the HCBS waiver programs, and all MaineCare services for persons, should not be part of a carefully-crafted redesign effort. In fact, it is noteworthy that, while Maine is in the group of states that has closed its state-run institutions, this state has and continues to favor out-of-home group residential placements over the provision of Supported Living or Family Support services¹. The new *State of the States in Developmental Disabilities 2013* (Braddock et al., 2012) reports that, even after Maine showed an adjusted spending increase of 63% over 2009 for supported living, our state ranks 21st in per capita spending for this service.

Maine's lack of funding for Family Support services is more dramatic in comparison to other states, although national reports indicate that nearly all states provide support for only a small portion of all families providing care for a child or an adult with an intellectual or other developmental disability. Maine ranks among the bottom eight states in its provision of financial support for families who are providing care for a family member with a developmental disability who receive any state funds. Only five percent of the estimated 11,785 Maine families in this situation are receiving family support dollars. (Source: Braddock et. al. *State of the States in Developmental Disabilities*, University of Colorado 2012.)

Medical Needs

The DD Council also agrees that attention should be paid to addressing the medical needs of persons with intellectual disabilities and autism, as well as other persons with developmental disabilities. There is a critical need to expand and improve the availability and provision of high quality and individually-appropriate health care services for persons with developmental disabilities, especially wellness services, preventive screenings and prompt, appropriate medical treatment. These services will address the higher risk for conditions such as obesity and diabetes, as well as other preventable secondary health issues that lead to much higher costs when not detected early.

¹ Supported living is defined for purposes of the data used in this document to include housing in which individuals choose where and with whom they live: ownership is by someone other than the support provider (such as the individual, family, landlord or a housing cooperative), and the individual has a person-centered plan that changes as her or his needs and abilities change.

Care Coordination

The DD Council welcomes the prospect of effective care coordination services to assure access to medical care for persons receiving waiver services, as well as others with developmental disabilities who do not qualify for Adult Developmental Services or are on one of the growing waitlists for the waiver programs. Along with intensive care coordination services, there is also a need for additional training for medical providers, to assure that individuals with intellectual disabilities or autism have access to “medical homes” that will welcome them and provide high quality, comprehensive and appropriate care to meet their individual needs.

This has become increasingly apparent to the DD Council through its work over the past five years with the Maine Departments of Labor, Education, and Health and Human Services in an interagency collaborative effort to address the needs of persons with autism spectrum disorders. Maine’s prevalence of autism spectrum disorders (ASD) exceeds national levels, which has created a sense of urgency to assure that Maine’s service systems are tooled and prepared to meet the needs of this population. The DD Council has worked particularly closely with Maine DHHS since 2010 under a federally-funded grant to develop and pilot model practices to improve early identification and early intervention services for young children with ASD, and access to quality health care services for those children not only during their formative years, but also as they transition to adulthood. We are also currently funding an outreach effort to collect detailed information from a group of individuals with ASD, their families and medical providers regarding barriers they have experienced related to transitioning from pediatric to adult medical care services.

We are particularly concerned by the anecdotal information we receive on a frequent basis regarding medical needs of persons with intellectual disabilities or autism going undetected. This is of even more concern when “behavior interventions,” including the use of psychotropic medications and sometimes inpatient mental health services are being utilized to treat “inappropriate” behaviors, without any investigation of possible underlying medical problems such as constipation or tooth decay.

We look forward to being able to work with the Department to assure that persons with developmental disabilities have access to the services and supports they need to allow them to achieve maximum independence, and participate as contributing and valued members of their communities.

Wait Lists

In regard to the work of the MaineCare Redesign Task Force and its report to the Legislature, the DD Council would like to offer one other final point at this time. While we hope our comments indicate our agreement that a carefully crafted and implemented redesign would be beneficial for the MaineCare program and people who are receiving services, we are extremely concerned to be sure that any estimates of potential savings that may accrue from providing Targeted Case Management services takes into consideration the growing waitlists for the waiver programs. With approximately 1,000 people with intellectual disabilities or autism waiting for waiver services as of December, 2012, and with the continuing budget shortfalls in MaineCare and the overall state budget, we are very concerned that the picture will only worsen. Any savings that can be realized through targeted case management and more

effective delivery of services for persons on the waiver programs should be recycled to assure that people with intellectual disabilities and autism have access to needed services and supports.

Thank you again for the opportunity to provide comments on the Redesign Task Force draft report. We look forward to continuing to work closely with the Department on issues important to persons with developmental disabilities and their families, and appreciate the careful consideration that this task force has given to all the information it has received.

Sincerely,

Alan Cobo-Lewis
Chair, Public Policy Committee

References

- Braddock, D., Hemp, R., Rizzolo, M. C., Haffer, K., Tanis, E. S., & Wu, J. (2011). *The State of the States in Developmental Disabilities 2011*. Dept of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.
- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., Lulinski-Norris, A., & Wu, J. (2012). *The State of the States in Developmental Disabilities 2013: The Great Recession and its Aftermath, Preliminary Edition*. Dept of Psychiatry and Coleman Institute, University of Colorado, and Dept of Disability and Human Development, University of Illinois at Chicago.
- MaineCare Redesign Task Force (2012, December 7). *MaineCare Redesign Task Force Recommendation Report Draft*. <http://www.maine.gov/dhhs/mainecare-task-force/november19-2012/MaineCare-Report-12-07-2012.docx>

